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ABSTRACT

The President's New Freedom Commission on Mental Health solicited public comment from stakeholders in the mental health community on various topics related to the Commission's mission. The goal was to gain a better understanding of the public's experiences with, concerns about, and hopes for the mental health care system. More than twelve hundred individuals submitted comments to the Commission on the following topics: access to mental health services; extent of coordination of mental health and support services; extent to which people with a serious mental illness or serious emotional disturbance live, work, learn, and participate fully in their communities; programs or practices that work well or improve your experience of care. The report is organized by the topics above on which individuals were asked to comment. Within each topic, frequently mentioned themes are highlighted and illustrative comments featured throughout. Nearly all stakeholders describe a system in which access to desired services is very problematic, resulting in over reliance on crisis management rather than effective illness management, and a wide range of systemic barriers are highlighted. The challenges of living in the community with a mental illness are another important theme, including the problems of stigma, unemployment, inadequate housing, inadequate income supports, and far too frequent involvement with the criminal justice system. The comments of these stakeholders clearly illustrate the very real challenges faced by America's mental health consumers and their families, and the service delivery system on which they rely. (GCP)

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PRESIDENT'S NEW FREEDOM
COMMISSION ON MENTAL HEALTH

A Report on the Public Comments Submitted to the President's New Freedom Commission on Mental Health

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Prepared for:

The President's New Freedom
Commission on Mental Health
January 7, 2002

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EXECUTIVE SUMMARY

The President's New Freedom Commission on Mental Health solicited public comment from stakeholders in the mental health community on various topics related to the Commission's mission[1]. The goal was to gain a better understanding of the public's experiences with, concerns about, and hopes for the mental health care system. More than twelve hundred individuals submitted comments to the Commission. Comments were submitted from all 50 states, the District of Columbia, and Guam, and from the full range of stakeholder groups, including mental health consumers, parents, family members, advocates, service providers, educators, researchers, and others.

The Commission solicited public comment on the following topics (number of individuals commenting on this topic is shown in parentheses):

1. Access to mental health services (767)
2. Extent of coordination of mental health and support services (946)
3. Extent to which people with a serious mental illness or serious emotional disturbance live, work, learn, and participate fully in their communities (710)
4. Programs or practices that work well or improve your experience of care (482)
5. Other comments (593)

Trained staff reviewed each comment and coded its content according to a coding scheme designed to encompass the full range of topical themes addressed in the comments. The coding scheme consists of 25 categories. Fifteen of the categories represent the Commission's Subcommittee areas, while the remaining ten categories represent broad themes that cut across Subcommittee areas and appear frequently in the public comments.

This report summarizes all the comments received through December 2002, whether by mail, email, or through the web site. The report is organized by the topics above on which individuals were asked to comment. Within each topic, frequently mentioned themes are highlighted and

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[1] This report was prepared by Westat under Task Order No. 280-99-1003, RFP No. 280-02-8073, and submitted to Claire Heffernan, Project Officer. The report was authored by Susan Azrin, Ph.D., Garrett E. Moran, Ph.D., and Mary Ann Myers, Ph.D., with assistance from Barbara Hatfield, Matthew Mishkind, Ph.D., Stephanie Peterson, Joseph Simons-Rudolph, M.A., and Margaret Tseng. M.S., M.H.S.

illustrative comments featured throughout. Copies of this report can be obtained from the President's New Freedom Commission on Mental Health web site at http://www.mentalhealthcommission.gov.

Nearly all stakeholders describe a system in which access to desired services is very problematic, resulting in over reliance on crisis management rather than effective illness management. Stakeholders describe a wide range of systemic barriers including inadequate funding for services and supports; gaps in service and provider availability; absence of culturally competent services; lack of systemic orientation to recovery; inability to obtain insurance; lack of mental health insurance parity; low benefit limits; excessive management of mental health benefits; poor coordination among mental health service providers, supportive services, and schools; difficulty enrolling in indigent care programs; and high service cost. The challenges of living in the community with a mental illness are another important theme, including the problems of stigma, unemployment, inadequate housing, inadequate income supports, and far too frequent involvement with the criminal justice system. The comments of these 1,205 stakeholders clearly illustrate the very real challenges faced by America's mental health consumers and their families, and the service delivery system on which they rely.

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BACKGROUND

The President's New Freedom Commission on Mental Health solicited public comment from stakeholders in the mental health community on various topics related to the Commission's mission. The goal was to gain a better understanding of the public's experiences with, concerns about, and hopes for the mental health care system. As stated on the Commission's Public Comment Web Site, "The purpose of obtaining public comment is to assist the Commission in formulating an action plan for the President that will improve America's mental health service delivery system." The web site offers a Spanish translation; translations in Chinese, Korean, and Vietnamese are underway. While most public comments have been submitted via the Commission's Public Comment Web Site, the Commission has also received written comments by mail and email.

Twelve hundred and five individuals have submitted comments to the Commission. Individuals submitting comments are asked to select their primary affiliation from a list of stakeholder groups. These stakeholder groups, along with the number of individuals posting comments in each group (in parentheses) are:

- Mental Health Professional/Provider (337)
- Consumer of Mental Health Services/Survivor (329)
- Parent/Guardian/Adult Caregiver (for children with emotional disturbances) (140)
- Family Member (135)
- Advocate (45)
- Private Citizen (37)
- Educator (16)
- Researcher (13)
- Other (153)

Trained staff reviewed each comment and coded its content according to a coding scheme designed to encompass the full range of topical themes addressed. The coding scheme consists of 25 categories. Fifteen of the categories represent the Commission's Subcommittee areas, while the remaining ten categories represent broad themes that cut across Subcommittee areas and appear frequently in the public comments. The topics included in the coding scheme are

presented in the following table, along with a count of the number of comments received on that topic.[2]

Table 1. Coding Categories for Public Comments

Group	Category	Persons Submitting Comments
Age	Children	293
	Older Adults	18
Special Populations	Consumer Issues	500
	Criminal Justice	91
	Families	131
	Homeless	23
	Rural	68
Services	Co-Occurring Disorders	74
	Employment & Income Support	219
	Evidence Based Practices	271
	Housing	104
	Medicaid and Medicare	174
	MH Interface with General Medicine	81
	Medication Issues	204
	Suicide Prevention	59
Access	Coordination of Services	314
	Rights and Engagement	280
	Cultural Competence	159
	Financing/Reimbursement	539
	Hospital	94
	Policy/Regulations (State or Federal)	172
	Managed Care	176
	Parity	98
	Restriction or Lack of Services	741
	Stigma	249
	Transportation	60
	Challenges in Community Life	340

[2] Note that the number of comments by topic will be greater than the number of people who commented, since each person could submit multiple comments and each comment might cover more than one theme.

The Commission solicited public comment on the following topics (number of individuals submitting a comment on this topic is shown in parentheses):

- Access to mental health services (767)
- Extent of coordination of mental health and support services (946)
- Extent to which people with a serious mental illness or serious emotional disturbance live, work, learn, and participate fully in their communities (710)
- Programs or practices that work well or improve your experience of care (482)
- Other comments (593)

Table 2. Number of Persons Submitting Comments by State

State	Number of Persons Submitting Comments
Alaska	5
Alabama	10
Arkansas	16
Arizona	22
California	93
Colorado	20
Connecticut	9
District of Columbia	2
Delaware	3
Florida	61
Georgia	13
Guam	1
Hawaii	2
Iowa	14
Idaho	2
Illinois	27
Indiana	18
Kansas	12
Kentucky	12
Louisiana	15
Massachusetts	36
Maryland	21
Maine	7
Michigan	44
Minnesota	26
Missouri	45

State	Number of Persons Submitting Comments
Mississippi	3
Montana	2
North Carolina	35
North Dakota	2
Nebraska	6
New Hampshire	11
New Jersey	44
New Mexico	8
Nevada	8
New York	64
Ohio	36
Oklahoma	13
Oregon	27
Pennsylvania	66
Rode Island	8
South Carolina	10
South Dakota	2
Tennessee	19
Texas	47
Utah	8
Virginia	19
Vermont	5
Washington	22
Wisconsin	25
West Virginia	7
Wyoming	1

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Table 2 above shows the number of individuals submitting comments by State. This report represents the findings from a review of the public comments submitted through December 2002. The 1,205 comments show a remarkable consistency across stakeholder groups. Stakeholders do vary in their perspectives of the mental health system, with family members and consumers often presenting emotionally charged stories from their lived experience with the local mental health system. Nevertheless, a number of shared views of the current mental health system emerge, cutting across nearly all stakeholder groups. This report summarizes those shared views and highlights the special concerns of certain stakeholder groups. Copies of this report can be obtained at the President's New Freedom Commission on Mental Health web site at http://www.mentalhealthcommission.gov.

The preponderance of comments reflects stakeholders' difficulties or disappointments with the mental health care system as currently structured. A few stakeholders commented positively on care received or experiences within the treatment system. But the comments primarily express concern over the current state of affairs, in many cases noting the difficulties of the stakeholder's personal situation and/or that of family members.

PUBLIC COMMENT FINDINGS BY TOPIC

Topic 1: Access to Mental Health Services

Inability to Access Desired Services

Nearly all stakeholders describe a system in which access to desired services is very problematic, resulting in utilization of less desirable crisis management alternatives rather than effective illness management. Consumer and family members address the difficulties they have accessing the particular kinds of services they need. Often, specialized treatment is not available, e.g., treatment for persons with posttraumatic stress disorder or for children with bipolar disorder. More frequently, comments simply address the lack of access to the services consumers need.

In extreme cases, the stakeholders describe situations in which the lack of mental health services leads to involvement in other systems such as criminal justice. Many stakeholders describe situations where a lack of appropriate mental health treatment seemed to have contributed to the consumer's incarceration.

Consumers and providers note that the lack of desired services leads to over utilization of less desired services that are often more expensive. For example, the lack of properly supported housing leads to unnecessary inpatient hospitalization. In some cases the services exist but waiting lists or lack of reimbursement render them inaccessible; in other cases the community just doesn't provide the service at all. This was especially true for those living in rural areas. But it is interesting to note that both providers and consumers discuss the difficulties with the overall service continuum, not just the presence or absence of particular services. Consumers and family members also note that access to services is difficult when they have no way of knowing what is available, and many express an interest in more consumer-run services.

Below we summarize stakeholders' comments on particularly desired services which they found difficult (sometimes even impossible) to access. In the next section, we describe the barriers to accessing these desired services, as identified by stakeholders.

Support Services

The Commission received dozens of comments about consumers unable to secure desired support services, particularly for supported employment, housing, and case management. These Michigan parents fight an uphill battle to secure their daughter appropriate treatment, and wish she could receive the support services that would allow her independence, particularly employment support.

> Our daughter does not get any support services other than getting her rent paid. No one helps her with her eating a good diet, getting her clothes washed or anything. We do what we can and now her total care has been left up to her family. She wanted to have a job but no one was there to help her ... She attempted to work but was fired due to a lack of behavior control. She received no employment assistance ... She probably could work part-time if she had someone to work with her and the employer like they are supposed to do but don't. ...We had a difficult time getting any services for our daughter. We finally obtained them through a court order.

A father from Tennessee writes about his adult daughter with schizophrenia:

> In spite of the fact that my daughter has been hospitalized several times, she has never had a caseworker. She had no help at all after she came home until we got her into the local mental health system. Some of the larger hospitals promised team meetings that were never held. Doctors never explained her illness and never offered suggestions about how I as a caregiver could help.

Family members caring for their adult loved ones with serious mental illness cite the lack of support groups for family members in this situation, as well as the need for more family member education. Parents of children with severe emotional disturbances tell the Commission they must curtail outside work to stay home and care for their disabled children, often resulting in financial hardship for those families who are already beleaguered with the cost of treatment for their children. A number of stakeholders stress that both parents of children with serious emotional disturbances and the aging parents of adult children with serious mental illness need support services for themselves, respite services in particular, without which they may become unable to adequately care for their disabled children at home.

A nurse writes:

> Families seem to be the most left out and they need all the support they can get to maintain equilibrium for themselves. It is extremely upsetting to have a loved one affected by mental illness. They fear suicide by their loved one or sometimes that there will be harm done to them or other family members if the affected loved one is violent in their illness.

Medications

Dozens of stakeholders tell the Commission that medications are absolutely critical to managing their mental illness and functioning in the community. Yet, they are often unable to obtain the needed medications, obtain the medication before their prescription runs out, or obtain competent medication management services. Many report long waiting periods for a medication evaluation or medications change appointment, often two or three months, and even up to six months. Family members and consumers describe legal problems or even incarceration that occurred when consumers went without needed medications, consequently became manic or psychotic, and were arrested.

Finding effective medications without severe side effects is a complicated process and usually requires multiple medication trials and the time to adjust dosages to the proper therapeutic level, many stakeholders report, yet it is often difficult to obtain these types of competent medication management services. Also important is education about each medication's side effects, which seldom occurs, according to many stakeholders. Writes one consumer:

> Most of us get 15 minutes with our doctor once a month or once every two months and a few minutes with a nurse periodically. This is not adequate time for those of us who need medications tailored to our individual biochemistry to get the attention necessary to put us on the best medications for us as individuals, at the lowest possible dosage with the least possible side effects. For those of us with serious and persistent mental illness, this is grossly inadequate.

Children's Services

A large cross-section of stakeholder groups notes a gross lack of quality services for children and adolescents. Many parents report there seem to be no services available for their children unless the child becomes suicidal or homicidal. Others note a severe lack of services for adolescents, in particular.

These Ohio parents write despairingly of their young son's involvement with the mental health system:

> When my son first became ill we were totally adrift ... help from the "system" was very difficult to obtain... He was hospitalized nine times the first year of his illness. He was 17 when the illness struck and 18 when the first year was over. When he was released from the hospital, local wrap-around services were almost impossible to obtain. Case management was fragmented, case managers seemed to have no training...some really tried and cared, but they soon burned out and left. Psychiatric appointments were months apart... medicines were prescribed with no education as to side-effects...twice we went to ER due to side-effects.

Many parents of school-aged children with serious emotional disturbance report that schools fail to meet (or sometimes even recognize) their children's special education needs in the classroom. A parent of a child with serious emotional disturbance writes:

> They public school offers a special education class but so far there hasn't been help with the main issue of his behavior. Also, the class is made of kindergarten through second grade. My son is second grade with no known learning disabilities and so is not challenged. Not progressing academically and not learning social and coping skills makes me wonder what is the purpose of this class.

A parent whose son died two years ago at age 22 years writes:

> He had ADHD, was bipolar and emotionally disturbed. All these conditions were present at his birth...The symptoms show up as behavior. I had a teacher complaining about him say, "If they would just give that kid the spanking he deserves, he would straighten out!" I asked if she advocated whipping to stop an epileptic seizure or diabetic coma. Of course, she indignantly said she didn't. I asked her, if that was the case, why was she advocating child abuse as a cure for birth disorders? The level of ignorance about what mental illness is (and what it isn't) is appalling.

Inpatient Treatment

While care in the community is always preferred, there still exists a need for hospital-based services, according to many stakeholders commenting on this topic. One mental health professional writes:

> The hospital is part of the answer. At times, people with a mental illness will relapse no matter how compliant they are with medication and needed services. For the most part, we can lessen the need for hospitalizations but never eliminate the need for them.

Dozens of stakeholders lament brief hospital stays of two to three days as insufficient to stabilize most acute care patients, as well as the severe shortage of inpatient beds in general, and for acute care needs in particular. Access to inpatient services for children and adolescents with severe emotional disturbances is cited as especially problematic, with children frequently placed in facilities in distant states, hours away. A family member writes:

> Recent experience with a family member was that the insurance company was only willing to pay for a person to be hospitalized for one or two days. They did not want the person to be hospitalized for the time required to stabilize them. I was forced to bring home my family member in such a drugged state that they could not function, but it was the only way to keep everyone safe. Even though the person was self-mutilating I was told the person was not ill enough to go to a State hospital...Our mental health system is woefully inadequate.

Consumers in crisis do not want to seek care at hospital emergency rooms, which are ill equipped to handle the needs of the mentally ill. Writes a provider from South Carolina:

> The State has closed acute inpatient beds due to budget cuts and clients needing inpatient care now wait for days in emergency rooms.

Recovery-Oriented Services

Many persons write the Commission that recovery from serious mental illness is possible, and many say they are living examples of this. Some of these individuals say the current mental health system is antithetical to recovery; the system relies too heavily on psychotropic medications and assumes that mental illness is chronic; "professionals" are the experts, and full recovery impossible. Instead, say these stakeholders, we need more recovery-oriented mental health services that recognize the individual with mental illness as the true expert on his or her disorder. These stakeholders mention consumer-run and peer support services as vital to recovery, but often unavailable.

A mental health advocate writes:

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> The one group of dedicated individuals who can educate clients about recovery and empower them with hope is a group of consumers.

The leader of one such group writes to the Commission:

> I run a support/activist peer-run group, and we are interested in working with traditional models, but we are finding a lot of resistance. However, many of the people I work with have found that they were only truly helped after they found a group like ours.

Services While Incarcerated

Correctional facilities are the mental health hospitals of forty years ago," writes one stakeholder. According to the comments received, dozens more stakeholders would seem to agree. Yet treatment is seldom available to inmates with mental illness. Stakeholders give numerous accounts of incarcerated persons clearly experiencing severe symptoms of mental illness, but receiving no treatment while incarcerated. One consumer writes:

> I was told I would have to wait until I got out to get treatment for my "problems;" I was in prison "to be punished, not treated.

Individuals put on suicide watch while incarcerated are treated particularly inhumanely, according to more than one stakeholder, including this family member:

> ...if the person is suicidal the treatment they receive in the jail facility is not sympathetic to a person who wants to take their life. For example, many jail facilities will remove the clothing and put the client in a padded cell all alone with just a camera in the room.

More than a few consumers report psychotropic medications were discontinued or denied while they were incarcerated. Writes one mother of her incarcerated daughter with mental illness:

> ...They are denied their medication even when it is provided free to the county, because I myself took it to the jail. It cost them nothing yet they refuse to administer it properly. She gets a pill whenever they feel like giving it to her. This is extremely dangerous...

Some stakeholders would like to see law enforcement officials trained on how to interact with persons with mental illness without escalating an already-agitated individual. Others would like to see similar training for judges and others in the judicial system, including juvenile justice.

Finally, according to a number of stakeholders in many states, once consumers have a criminal record, upon release they cannot access any public mental health or support services, particularly subsidizing housing, making re-entry into the community particularly harsh.

Suicide Prevention

Family members describe situations where they firmly believed their loved ones were dangerous to themselves and/or to others, but the family members were unable to get their loved ones the needed crisis services. Some family members and stakeholders describe crisis services that were so brief--one to three days--that their loved one was far from stabilized when released to the family member's care. Other family members report only being able to obtain crisis services once their family member actually attempted suicide or was arrested. Consumers also wrote of having to wait extended periods of time for crisis services while feeling suicidal.

More than a few people tell the Commission of how they lost their loved one to suicide.

> I am the mother of a child who completed a suicide while on suicide watch on a Mental Health Unit in a hospital. The safety precautions and standards of care were grossly inadequate to provide the promised safety. My son, xxxx, aged nineteen, self admitted after experiencing an undetermined psychosis that included auditory hallucinations and suicidal ideation. We were repeatedly assured of his safety...The "professionals" responded to our queries regarding levels of safety with dismissive comments such as "we are the professionals." Our concerns were generated by the level of monitoring, the presence of tearable sheets and other safety factors. We were told to "leave it up to us, we know what we are doing." On the evening of the third day, xxxx took a sheet from his bed, went to the bathroom and completed his suicide by hanging. ...What I have found in the time following xxxx's death is that this issue of completed suicides while in hospital or other institutions is prevalent and yet there are few efforts to hold systems accountable. There are nonexistent or inconsistent levels of safety under such conditions throughout the nation.

Services for Substance Use Disorders

Numerous stakeholders cite a dire need for substance abuse services, particularly *simultaneous* treatment of co-occurring mental illness and substance use disorders. Many stakeholders report difficulty in accessing these services or long waiting lists.

One provider elaborates on this treatment need:

> Dual diagnosis is one of the most devastating problems that we have experienced today for both children and adults. Many times we talk about prevention, but nowadays we are avoiding the issue of treatment...All too often, clients are moved around a system and told they must treat the mental illness part before the substance abuse part can be treated and vice versa. In reality, both must be treated at the same time.

Another mental health professional writes:

> ...Patients with dual diagnoses are often neglected by all services. Substance abuse professionals are not experienced with dealing with mental illnesses; mental health professionals are not very comfortable or knowledgeable with persons with substance abuse...

Services for Older Adults

The relatively few comments received on services for older adults note the overall lack of mental health services for this population. As summed up by one stakeholder:

> ...Services to the geriatric population have become lost in the shuffle.

Rural Services

Consumers in rural areas need and desire the same kinds of mental health services as do those in more populated areas, according to rural area stakeholders. But for consumers in rural areas, the lack of access to all types of mental health services is apparently more extreme.

One rural stakeholder explains:

> Living in a rural area makes receiving services difficult--if not impossible. We lack transportation services over county lines. We lack choice or providers. Staff turnover in rural areas is high; people leave to find better paying jobs in larger cities.

Other rural providers write:

> The number one comment I hear from our consumers is that being in a rural area, it is difficult to travel to and from appointments for services.

In our rural area, our nearest providers are approximately 45 miles away.

Barriers to Accessing Desired Services

While the previous section addressed the types of services that prove challenging to access, this section discusses the types of systemic barriers that stakeholders believe limit access to care. Many stakeholders offer insightful comments on this topic. Dozens of comments reflect problems related to insurance coverage, managed care, and the cost of services. Stakeholders express frustration, for example, with not being able to access a desired service because of the lack of mental health parity, or the limits imposed by managed care utilization management.

Stakeholders also discuss barriers resulting from inadequate numbers of qualified service providers, especially psychiatrists to prescribe and monitor medications. Cultural competence is a theme addressed in a limited number of comments, but one that paints a compelling picture of the barriers faced by those from different linguistic or cultural groups. In rural areas in particular, stakeholders comment on the dearth of providers and the lack of transportation presenting a barrier to service access. The following sections discuss each of these concerns and others in more detail.

The comments present many different cost-related barriers to accessing treatment. Just looking at the topic of insurance coverage, care management, and costs, the list grows quite long, and includes:

- Lack of parity for mental health service benefits;
- Strict limits on authorized numbers of days or sessions of treatment;
- Strict annual and lifetime limits on coverage;
- High co-payments or other out-of-pocket expenses;
- Provider drop out due to too low reimbursement rates;
- Limited provider panels;
- Invasive and time consuming service authorization processes;
- Unskilled or insensitive service authorization personnel; and
- The inability to purchase insurance coverage due to pre-existing limits.

Lack of Parity in Mental Health Insurance

Consumers and families make a number of points about the lack of parity for mental health insurance and the problems it causes:

> There is an overwhelming need for parity in insurance reimbursement for mental health services as compared to coverage for other health services. We are a middle income family with copay insurance through an employer but have had to spend many thousands of dollars of our own money in getting treatment and medication for our daughter. If another organ of her body, other than her brain, were malfunctioning, the coverage would be much better.

> The biggest barrier I've had to deal with is my insurance company. . . . I have a good insurance plan when it comes to my regular doctor visits. However, my copay for a psychologist or psychiatrist is double the amount of when I see my family doctor (or any other specialist). This seems like discrimination to me.

Limited Provider Panels

Consumers and family members also express frustration with the limited number of providers who are available to provide services in their health plans:

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> The last hurdle I've faced is the small amount of psychiatrists that deal with insurance companies. . . . The psychiatrists who do accept insurance are so busy, it's nearly impossible to get an appointment with them.
>
> We need more choices under our health care plans for specialists like a child psychiatrist who treats . . . our child. . . . It should not take six months to access help when your child is . . . depressed and causing complete chaos in the lives of all those around them. It is not OK for a child to not receive help because the waiting list is too long.

Limited Mental Health Care Benefits

Another theme that appears often relates to the limitations on mental health care benefits and the consequent high out-of-pocket costs that consumers and families then must pay:

> I live in a state . . . with a parity law, yet still find my mental health managed-care provider . . . has continued to limit my access to care. . . . . How can I be expected to get well when I'm always worrying about access to care?
>
> First of all, [the insurance company] limits the days that they will provide coverage (in my instance, 20 some days for a whole lifetime). And mental illness treatment is so expensive, it's almost impossible for the typical middle-class person . . . to pay for it out of their own pocket.
>
> The cost of mental health care has also been a constant stress in my life. I have a good insurance policy but my benefits are limited to a preset number of visits . . . which are [soon] used. This leaves me with between $350 to $500 of unreimbursed mental health expenses a month.

Managed Care Barriers

Providers also stress that managed care has limited access to services for the people they serve:

> Managed-care has decreased the amount of services available to the patient (i.e. decreased number of sessions, decreased amount of care, limits to practitioners) and demanded more of the practitioner (i.e. paperwork and disclosed personal information about the client). These practices are detrimental both to the practitioner and to the client.
>
> . . . many times, managed-care has made it impossible for clients to receive the care that they need because of undue restrictions on their care.

Reimbursement Levels

Providers also expressed frustration with the low reimbursement levels available from insurers and managed-care organizations, a perception received sympathetically by at least some families and consumers:

> Managed-care has taken the most poorly reimbursed field of health care and made reimbursement so limited that providers are quitting in droves or not accepting insurance from managed care companies. Something must be done to create parity across the board on a national level with better reimbursement to the provider, to afford providers with a living wage.

> . . . the reimbursement insurance companies give to psychiatrists is ridiculously low . . . I don't see how [my son's psychiatrist] could make a living on what they want to pay him, and don't blame the doctor for dropping out of the plans.

Lack of Insurance Coverage

Many of those with limited family resources and without insurance have even more serious challenges to face:

> The main barrier I face at this time is my inability to obtain health insurance. I was originally carried on my husband's policy, but when he changed companies.....everyone in the family EXCEPT me was picked up for coverage. I have yet to find a company who will cover me independently. . . . I find it very frustrating that . . . I am now sometimes non-compliant with my medication for financial reasons.

Obtaining SSI and Medicaid Benefits

Those who are indigent and theoretically eligible for publicly funded mental health benefits face a different but equally difficult set of problems. They may have to establish eligibility for Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) in order to receive a very modest monthly income support and become eligible for Medicaid or Medicare. As a practical matter, the entry barriers for these programs are hard for many consumers to

surmount without assistance, according to many stakeholders. Becoming eligible for SSI, for example, may take many months and sometimes requires appeals.

Noting the complexities of negotiating her mental health center's paperwork, a counselor observes that gaining SSI benefits is much tougher still:

> I believe, however, that the process of receiving services from a mental health center is simple compared to applying for state benefits or SSI/SSDI. Both of these processes are very challenging and often that is an area that we can assist persons with.

State Budget Cuts

Several comments from providers address the impact of historical and recent state budget cuts on the availability of mental health services, as illustrated in this statement from a community case manager:

> Our target population is the severely mentally ill and those with no income. Our state is in a crisis situation with hiring freezes, budget cuts, and staff are not being replaced to work with the consumers that need help. We don't feel like we can do our jobs well and take care of our consumers spread too thin.
>
> Access to care for patients experiencing significant crisis (requiring hospitalization) is disappearing to those without resources. In SC, the state has closed acute inpatient beds due to budget cuts and clients needing inpatient care now wait for days in emergency rooms. . . . Our local mental health center (also state operated) is trying to help and around the state local communities are coming up with some solutions, but it's all patchwork to off-set the lack of inpatient capacity. This problem is not limited to SC—through my professional associations I've heard of similar problems nation-wide.

Another provider comments on the impact of these budget reductions on people with serious mental illness:

> Prior to recent state budget cuts this year our mental health agency was the safety net for the uninsured. However, now people can have access to our services only [if they have Medicaid or are in an urgent crisis]. If someone . . . does not have

> insurance . . . they are unable to afford their medications. . . . Once these medications run out his/her symptoms again exacerbate and the revolving door begins.

Stakeholders also cite a wide range of reasons for current and sometimes growing shortages of essential services and service providers that are less directly related to cost. Services frequently mentioned include psychiatrist visits, inpatient hospital beds, ACT teams, and case managers, among others.

Unintended Consequences of Olmstead Plan Implementation

For example, a stakeholder in Colorado concludes that Olmstead Plan implementation has had an adverse effect on the availability of inpatient beds in that state.

> A perhaps unintended consequence of the Olmstead decision has been that it was used in Colorado as an excuse to close additional state hospital beds, where we were already SEVERELY under supplied with beds for the most severely ill patients. No additional funds came to the community as a result of these closures. Consequences (all of which can be documented):
>
> - More severely ill children/adolescents sent out of state due to lack of local resources, cutting them off from family support;
> - More suicides in jails as severely mentally ill inmates wait for beds to open up at state hospitals; and
> - More patients released far too quickly from the hospital, or never sent there when they need that level treatment, resulting in more severely mentally ill homeless or recycling repeatedly through emergency rooms.

Psychiatric Inpatient Unit Shortages

A nurse in Florida tells us of the closure of a psychiatric inpatient unit on which she works after her hospital was acquired by a large national hospital chain:

> Our unit recently closed its doors with only a 30-day notice. No consideration was taken in advance on what to do with the community's mentally ill. . . . Law enforcement has been inundated with calls for help and no where to take these people due to lack of services. Some are being housed in the jail and law enforcement agrees that this is not appropriate. The impact of this on our community will be enormous.

> These people are a part of our community and it is our obligation to see that they get the help they need and deserve.

Another comment notes the limited number of treatment professionals and hospital beds:

> The only barriers I see is that there is not enough mental health professionals to treat clients! . . . We need to do more in getting more hospitals open and more staff that fit the needs of our clients!

Lack of Services for Homeless Persons with Mental Illness

A mental health consumer in Southern California who has experienced periods of homelessness describes the lack of service availability in his home community:

> There is a lack of mental health services in the community that are voluntary, friendly, competent and accessible. A number of years ago I was on the streets delusional and hearing voices for nine months in xxxx, California. You might have seen people like me... ragged hair and beard, very dirty and loudly talking to oneself. I asked for services at the shelter and the sheriff's station and was turned away. There was a missing person's report my conservator placed on me and when the police checked my ID they failed to connect. I sat in the waiting room of the county hospital for three days and was turned away. I stood in front of a bus and refused to move hoping that I would be taken to the hospital or the jail, but even that didn't work since I was physically removed by two passengers on the bus. This went on for nine months until someone took me and called my parents who had me admitted to the hospital where I received medicine that got rid of the voices. I would like to say this changed with the years, but it hasn't. In affluent xxxx, there are still no services for the homeless mentally ill.

Lack of Transportation

Another frequently recurring theme in the comments is that the absence of transportation presents a barrier to the receipt of services, particularly in more rural areas.

> There is no centralized, consistent method for accessing mental health services. For children, there is no system. Therefore, people do not know who to call or where to call. MH services are not accessible to many because Iowa is a rural state. Services are not consistent from rural to urban areas. The bulk of our psychiatrists are located in 2 counties out of 99. A barrier to access is

transportation. The distance to services might be 30-90 miles or more, there is no public transportation and people do not always have cars or money for gas.

There needs to be early identification and schools provide the ideal setting in which to do so. For kids, access would be enhanced if services could be provided in the school setting. . . . There are great benefits for kids to after school treatment programs and partial hospital programs however access is often limited due to lack of transportation.

The closest state mental-health clinic around here is 60 miles away. When you get there you have either two minutes with a very busy psychiatrist or 15 minutes with a cold, uncaring social worker. The only topic of discussion is the medication you are on. There is no psychotherapy offered for depression, anxiety, or PTSD. There is public transportation available if you are on disability or Medicaid. There needs to be help available in every little town in this country for mental illness, just like there are for other kinds of illnesses. If our local 26 bed hospital can get a CT scanner, then why not a psychiatrist?

Coercive Nature of the Service Delivery System

Some consumer comments indicate that the coercive nature of the service delivery system is a major barrier to accessing services:

Access is limited by cost, numbers of programs, and, in some cases that I have witnessed, the extremely coercive (and potentially violent) nature of the services which people quite reasonably avoid for fear of entrapment in a system that will keep and/or harm them. . . . In my mind, access is a secondary issue until involuntary treatment is eliminated.

Another consumer describes how coercive treatment adversely effected his self-respect and willingness to accept further treatment services:

When I first entered the mental health system in an acute state of panic and anxiousness, highly agitated, very severely depressed & extremely suicidal, I was treated with care, concern, validation and respect by the person who did the in-take and whom later became my first case-manager. . . . That would not prove to be the case however with any other mental care provider I engaged in services with since. . . . The later use of coercion and outright force was to be the most severe and persistent causation for my having a lack of access to needed services and supports. . . . It was such re-traumatizing and stressful experiences which brought harm to and therefore caused a serious hampering of what quality of life I

> may have still had or ever hoped to regain. . . . Such experiences dug away at what little dignity, pride, self-respect and self-worth I once held. . . . Coercive and forced treatment, as well as psychiatric incarceration, in any form are major and significant barriers to true informed consent, choice and treatment of any form of health care which may have a chance to improve or enhance the quality of life for an individual who may seek it.

Civil Commitment Statutes

Also common are comments from family members or service providers who feel that the current civil commitment statutes prevent people with mental illness from receiving the services they need:

> California law which says you must be a danger to self or others or gravely disabled before you can be involuntarily treated is a barrier to treatment. The severely sick often say they are not sick and so they remain untreated until a crisis occurs. . .
>
> Involuntary commitment laws must be more broadly interpreted so that those who are unaware of their illness can be brought into care. Here, access to services is denied because people "choose" not to receive it. The "system" has been hiding behind this preposterous notion of "choice" too long. Mental illness can destroy a person's ability to make appropriate choices for their own care.

Culturally Competent Services

Stakeholders mention the unavailability of culturally competent services and service providers in a number of comments. A mental health professional writes:

> Minority populations continue to face significant barriers to mental health care. Language continues to make mental health services inaccessible to large numbers of people. One reason for this is lack of qualified mental health providers who speak languages other than English. Even in xxxx, [California], with over 10 educational programs graduating hundreds of Psychologists and Counselors every year, it is almost impossible to find Spanish speaking mental health providers....
>
> I believe that the most significant contributors to this issue is the high cost of education, the lack of adequate reimbursement when serving minority and underprivileged communities, and the lack of incentive to become a mental health professional. Doctors, lawyers, and teachers are all eligible for large reductions in

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> their student loans if they serve underprivileged populations-not so with mental health providers. If we valued mental health as we valued medicine and teaching, we would offer incentives, such as loan forgiveness, to individuals willing to go to school and return to serve their communities.

Another provider offers an example of the sort of misunderstanding that can arise when someone is unfamiliar with the customs and norms of a particular culture:

> ...I have had Hispanic clients, in my office, make a call to the Hispanic intake and had the intake person ask what the problem is. Southwest Hispanics generally say "a family problem" [to describe a mental health problem], when speaking to a stranger. The worker then told the client that family problems aren't covered and hung up....

The absence of culturally competent service providers is also a problem for people who are deaf or who have hearing impairments. An advocate writes:

> ...From referral to actual intake has taken, in some cases, up to a full school year because the MH system is not prepared to work with or deal with deaf and hard of hearing individuals. In addition, these individuals are often placed in day treatment or group settings where there are no sign language interpreters, assistive listening devices or other assistive technology made available. There is little to be gained from the "group" experience if you cannot even communicate with your peers.

Topic 2: Extent of Coordination of Mental Health and Support Services

Stakeholders often note that coordination represents a major issue within mental health treatment as well as between mental health and support services, e.g., the physician prescribing psychotropic medication did not coordinate with the outpatient counselor. Stakeholders also mention the influence of separate funding streams, which discourage coordination of care. However, stakeholders most often discuss the lack of coordination of mental health and support services in terms of *limited access to desired services*, so that the problem is not just that services are not coordinated, but that the services often aren't received at all.

The preponderance of comments on coordination of services indicates that the array of services that should be accessible and coordinated is absent. Many write the Commission that the point of contact within the treatment system fails to offer the type and frequency of services which consumers and their families are looking for. The remainder of this section discusses stakeholders' most frequent comments on particular types of coordination within and between mental health services and support services.

Breakdown in the Continuum of Care

According to dozens of stakeholders' comments, the mental health "continuum of care" represents an illusive ideal, not the reality of our current mental health care system. Across all affiliations, stakeholders say the mental health system of care is comprised of discrete services, none communicating with the other, with the existence of support services only sometimes revealed to those most in need of them.

Dozens of consumers and family members write about how hard it is to find desperately needed support services, particularly while one is struggling with the symptoms of a serious mental illness. This consumer's comment reflects the thoughts of many others:

> I have found that little coordination exists. I have had to be proactive in finding the resources available to me. I was never made aware of vocational rehabilitation services, or aware of drug company-sponsored indigent care for medications. I had to search these things out myself, which was extremely difficult to do in the worst episodes of my illness. My ability to concentrate was so diminished that I think I missed many opportunities that could have helped me to be successful.

Another consumer describes a hodgepodge of services that the consumer is left to navigate alone, when what the consumer really needs is something else entirely:

> There is very little integration between programs. Rather, we as consumers are shifted from one program to another with little continuity. Start at the emergency room to calm down from an acute episode; shifted to an inpatient wing or state hospital; released to a day treatment program; learn skills like pottery and painting and then be released to one's family or the streets or the prison system. Then the consumer is expected to find his way into job training or educational programs without a single case manager supervising his progress. What each consumer needs is a single social worker/case manager monitoring one's progress through the system, making sure that a consumer is treated with dignity, offered the best practices available, guided through rehabilitative/recovery services, helped into community based mental healthcare and/or housing, guaranteed supportive psychotherapy and medication management, and employment placement so one can thrive over the long-term.

A parent describes the poorly coordinated services her daughter received:

> My daughter has been hospitalized 17 times since her diagnosis for bipolar illness ... Although our county mental health system is supposed to provide a caseworker, and timely visits with a physician so that she can maintain her health, this has not happened. I see little coordination between her physician, social worker, and the "team" that she is supposed to have access to. The latest failure in services is that my daughter has not had a regular check-up with her mental health physician for 8 months. If it were not for the support from her general practitioner, my daughter would not have survived this system. Lack of funding and poor management put too many people like my daughter at risk. This is inexcusable and unacceptable.

A provider describes the lack of information sharing among service components that she has experienced:

> When clients are treated at either State facilities, local hospitals, or the ER, information regarding any change in treatments is not communicated to the provider that routinely cares for the clients. Treating facilities should be mandated to communicate with the provider that will be caring for the client once they leave the facility. Far, far too often I have received a client after a hospitalization with no information as to what tests have been completed, or what changes in medication have occurred. I may repeat test, an added cost to the system.

Finally, one consumer sums up the sentiments of many stakeholders:

> The connection between mental health, substance abuse, homelessness, and criminal justice must be fully explored and dealt with across systems. A large percentage of people who are chemically dependent, homeless, or in prison have, a mental health diagnosis.

Coordination of Children's Services

The same types of coordination and continuum of care problems noted in the previous section exist for children as well, but also extend into the education arena, according to numerous stakeholders. Because of children's multiple developmental needs, multiple agencies are often involved, complicating the coordination of services even further.

A parent writes:

> There has been very little coordination of services provided with our children's services. We have searched for five years to find respite providers...We have attempted to find a competent therapist with knowledge of adoption and significant emotional challenges and still continue to search.

Another provider addresses the disjoint between adult and child mental health services and the lack of coordinated family services:

> I have worked in child mental health services for 35 years as a clinical social worker. I find an appalling lack of coordination between the adult mental health providers and the child providers...There seems to be little acknowledgement that many of the parents whose children are in the "system" also have a mental illness...In spite of two systems which provide case management for the child and the adult, there is no system which really addresses family issues...The child system continues to expend large sums of money on the child without ever addressing the issues parents with mental illness bring to the situation.

Integrated Treatment for Co-Occurring Disorders

Stakeholders of all affiliations frequently note the lack of coordination between drug and alcohol and mental health services. Many also point out that in most States separate funding streams fund mental health and substance use treatments. Consequently, they are typically administered in two entirely separate systems, making coordination at the individual consumer level unlikely.

A mental health professional writes:

> ...There is a definite lack of coordination of mental health and support services for the dual diagnosis population...Some agencies follow an abstinence only philosophy, and refuse to treat clients who are actively using. As a result, many people in desperate need of services are turned away and do not know where to go for help.

An advocate agrees:

> There is a huge gap in care for dual-diagnosed clients, since hospitals won't take a substance abuser, and treatment centers won't take someone who needs psychiatric medications.

Individuals with a mental illness and co-occurring substance-use disorder report seldom receiving treatment for both disorders simultaneously, even when the treating clinician is clearly aware of their substance-use disorder. In fact, substance use treatment is entirely inaccessible, according to a number of stakeholders. Not surprisingly, a few consumers write the Commission that integrated treatment for co-occurring disorders, considered an evidence-based practice for adults with serious mental illness, is unavailable.

Further compounding this service coordination problem, individuals with co-occurring disorders often find access to other support services limited, as this provider describes:

Often the clients that have the greatest difficulty are those individuals that experience mental illness and addictions. Their relapses preclude them from participating in a number of housing options and they are often punished by having housing programs denied to them simply because they have trouble staying clean and sober. Unfortunately, relapse is an inherent part of the disease of addiction and these individuals need to be supported even if it requires "wet" housing alternatives.

Family Involvement in Treatment

Many family members of individuals with serious mental illness want to be allies in their loved ones' treatment, but find themselves left out and uninformed of treatment plans and progress. Family members report this occurs even when they are the primary caretakers for their loved one with mental illness.

One family member writes:

> When my son first became ill [at age 17 years] we were totally adrift...help from the "system" was very difficult to obtain. He was unable to remember appointments. Confidentiality was given as the reason we, as his parents, could not be advised of date and time of appointments. Therefore, he did not receive needed help. He was hospitalized nine times the first year of his illness. Each

> time he missed an appointment our insurance company was billed...It was totally absurd—not cost-effective or treatment-effective.

Another frustrated family member describes how the system's lack of information sharing with the family may have impeded treatment for their daughter:

> For example, in the six years she was being treated for her bipolar illness at the county mental health department, no one ever informed our family, in spite of my daughter having given full disclosure instructions for our inclusion in her treatment plan, of her "dual diagnosis." When this fact was finally revealed, she made plans to enter into a local outpatient program designed for dual diagnosis patients and her recovery began in earnest and she has progressed exponentially since that revelation. It is inexcusable that she should waste several years of her life to an illness that is so treatable and through so much delay and misinformation, especially when she has an educated and supportive family to help her.

The Ohio parents of a young adult son with mental illness write,

> There is very little coordination between hospitals and local agency. Once, even though we were dealing with a private hospital and my son had insurance, the hospital released him without notifying us. If he had not had a quarter in his pocket to make a collect call, he would have been on the streets. His father went to bring him home while I stayed on the phone telling him "please stay there, don't leave"...

Mental Health and General Medicine Interface

A number of stakeholders observe the separation of mental health care from other health care services and the problems this separation causes.

This provider's comments on this topic are typical:

> There is a huge and artificial disconnect between the mental health system and the clinical medical system. In the end, this disconnect creates much more cost, and is a major disservice to patients.

A family member writes:

> The practice of separating mental health care from other health care results in problems getting blood work, EKGs, and other tests...ordered by the psychiatrist in order to monitor medication side effects.

Some stakeholders decry the larger medical establishment's lack of awareness of mental disorders. Writes one consumer:

> ...Physicians should be more aware and educated on mental disorders...I was misdiagnosed as having a possible thyroid cancer and had to undergo expensive e-rays and a biopsy only to tell me that there was nothing wrong with me. I took several trips to several different doctors to finally come to the correct conclusion that I suffer from panic disorder.

Noting that people with mental illness generally have poor physical health, one provider suggests that mental health providers need to pay more attention to their clients' physical health needs. Conversely, a number of primary care physicians, particularly in rural areas, report that they frequently have responsibility for identifying and treating their patients' mental disorders, as specialty mental health providers are seldom unavailable in rural areas.

One family physician reports,

> In rural settings, there are not enough psychiatrists available to treat patients...As a family physician, I treat successfully all age groups of mental illness. Compensation for treatment and evaluation for my patients with mental illness is often not paid because I am not considered a "mental health provider." Who else will provide this care for these patients?

Primary care physicians also treat persons with mental illness in more populated areas. According to one family physician:

> Many patients with mental illness go to their regular medical doctors for treatment due to stigma of the diagnosis, unavailability of psychologists or psychiatrists, and limited mental health benefits by third-party payers.

Topic 3: Extent to Which People with a Serious Mental Illness or Serious Emotional Disturbance Live, Work, Learn, and Participate Fully in Their Communities

Stigma

For all stakeholders, the issue of stigma emerges as central to the discussion of consumers' participation in community life. Consumers fear disclosure of their mental illness will effect their employment, access to health insurance, friendships and daily activities. Many consumers and family members give examples of the negative impact of disclosure of mental illness. Numerous comments underscore the need for training and education of employers, consumers, and community members to end the stigma associated with mental illness and reduce barriers to participation in community life.

A parent from South Carolina, reflecting on the response of friends and acquaintances to her daughter's bipolar disorder, writes:

> When I recently told someone a family member had cancer, I was embraced. When I tell people that my mother had diabetes and lost both her legs, they are sympathetic. When I tell someone my daughter has mental illness, I feel an immediate withdrawal. No embrace, no sympathy - but fear. People do not want to be around mental illness. ... Our loved ones did not choose to have this illness. Who would? But they are not monsters. They are beautiful, loving and precious people who are suffering not only physically and mentally.

Consumers also give eloquent testimony to the anguish they suffer in not being able to participate fully in a "normal" community existence. Their comments reflect the daily discrimination they are subject to, from employers, co-workers, teachers, neighbors and law enforcement officials who do not understand and are not sympathetic to their illness or that of a family member.

A family member from Pennsylvania describes her family's abandonment by their community as a result of her son and husband's mental illness:

> My 15-year old son was diagnosed with bipolar approximately one year ago. This came after my husband was also diagnosed after he had a manic episode, which resulted in the loss of his job of 23 years, and a felony conviction ... It is

> extremely difficult for him to participate in the everyday activities of life... It is extremely difficult for him to find employment, and he has been unable to do so for over a year. The stigma attached to mental illness is overwhelming. We have been looked down upon in our community, and there is a lack of understanding within our community. Our children have suffered at school, and many of their friends have been told to 'stay away from them.' My son, who was a school wrestler, had to leave the team after his teammates would no longer practice with him. We were always very active in our community but no longer participate in any community activities, as people turn away from us. My children are not allowed to play in our community sport teams, as the perception is no other children would want to play with them, they would not be able to place them on a team ... I see no light at the end of the tunnel.

Need for Support Services

Lack of the support services that would make participating in the community possible is noted by many, especially the need for job training and access to employment. Numerous stakeholders describe how insufficient SSI or disability payments are in meeting one's living expenses, particularly when coupled with the high price of medication. Furthermore, they note, conflicting regulations make it difficult to work without losing necessary health benefits, especially coverage for treatment and medication. Stakeholders also cite support for independent living and structured rehabilitative care that teaches daily living skills as insufficient or missing support services.

One consumer writes:

> A key barrier [to full community participation] is lack of basic human needs being met, such as decent jobs at decent pay, decent housing...We need more housing, not just more Haldol.

Employment and Income Support

Many, many stakeholders tell of consumers' desire to work in a job, but the seemingly insurmountable barriers that stand in the way. These barriers include finding a job, despite sometimes lengthy periods of unemployment; finding a sympathetic employer who will hire someone with a mental illness; the risk of losing medical and drug coverage; and employers' unwillingness to provide accommodations such as flexible schedules or time off when needed. Yet, without a paying job and the social status, financial rewards, and meaning contribution to

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society that work entails, there is limited opportunity for full participation in community life. As one consumer tells the Commission, "Work is the 'sine qua non' of life."

One advocate sums up the comments of many:

> ...Everyone wants a valued place; jobs, contributing to community, is part of that valued place.

Stigma and employment discrimination against persons with mental illness was mentioned by many as a major barrier to employment. This consumer's comment reflects the thoughts of many others:

> We are just not there yet. Employers don't want mentally ill people to work for them. The news on TV, Radio, and in the newspaper, only talk about the people who have committed a crime, usually a murder.

Many consumers write that the current disability benefit structure has built in disincentives that discourage attempts to seek employment. One frustrated family member describes this dilemma:

> If the individual goes back to work, even low-paying job or part-time, he or she jeopardizes their coverage. They can't risk losing the medical and drug coverage!!! What they supposed to do? You want them to recover and become a productive member of society. But individuals with mental illness have relapses, etc. They require constant medical care with access to the necessary drugs to maintain normalcy.

Numerous consumers decry the poor quality of the vocational rehabilitation services they have received:

> I am unemployed and voc rehab, the three times I tried going through them, was about the biggest joke around. I was placed in made up nonexistent jobs, like a receptionist at the county museum, a place that got really no visitors, maybe one a week. I just sat basically. And then there would be, every month, a meeting with caseworker, boss, skills trainer, to discuss how I was doing at this farce of a job. Huge waste of money and did nothing for me.

This consumer suggests that many persons with mental illness could work if afforded an appropriately flexible work schedule:

> The most serious issue, I believe, is the assumption on the part of employers and disability programs that persons are either "fully functional" or "totally and permanently disabled." This kind of dualistic thinking substantially reduces the potential productivity of the population of persons with mental illness...I have bipolar disorder. I am able to work 40 hours a week, but it's not a consistent 40 hours. Some days it's 9-5, some days 10-8, some days just a few hours, some days not at all. When I'm experiencing a mild manic episode, my productivity is very high. When I'm depressed, it's low. I have an IQ of 140, yet the work world doesn't value intelligence or productivity, it values attendance. I have the ability to do many jobs, but the hours must flex for me to handle them.

Like this consumer in California, a number of stakeholders comment on the near-poverty life one must live on disability benefits:

> The worst by far is that the mentally ill that are on Disability are doomed to live in poverty or accept low paying part-time jobs because of policies that discourage saving or earning enough money for a livable wage.

Housing and Homelessness

Everyone needs affordable, safe housing, and persons with mental illness are no exception. Yet, such housing—or even any housing at all—is typically very difficult to come by, according to many stakeholders. Some stakeholders cite subsidized housing waiting lists of two years or more. The lack of transitional housing causes many consumers to end up on the streets when discharged from the hospital because they have nowhere else to go. Consumers without a decent place to live in the community cannot be said to be "participating fully in community life."

Mental health professionals write:

> It appears to me that the problem with current system is that there are people who can no longer stay in the mental institutions but there is no where else for them to live. I work in the residential care area for people with mental disabilities. I am faced everyday with the issue of someone needing a place to live but having no way at all to pay for it themselves.

> There is not enough 24-hour supervised transitional housing for psychiatric consumers. The waiting lists for this type of housing are two or more years long. This shortage of housing leads to hospital overcrowding and homelessness. There is resistance from most towns when a group home needs to be opened, which hampers efforts to create more housing even when funding is available.

> People with serious mental illness need HOUSING and better income supports to live in our communities.

A consumer describes the lack of preference consumers are afforded in choosing their housing:

> For the most part, housing services are not "real world" services. In other words, consumers are given a roommate that's not of their choice, or they're not allowed to have a television, etc. In the real world, people know the rules because they are in the form of a lease. In the real world, people choose either to have a roommate or not, or choose to live alone.

Criminal Justice Involvement

Failures in our system of community mental health care have led to the tragic overuse of the criminal justice system and the jails to address the problems of people with mental illnesses who are homeless or in crisis. A stakeholder from Missouri points to the overuse of the jails to house people with mental illnesses:

> Few will argue that jails and prisons have become the mental hospitals of 40 years ago. Statistics abound on the percent of inmates who have a concurrent mental health and/or substance abuse diagnosis.

Another stakeholder outlines the process that leads consumers of mental health services to end up in jail:

> There is very little coordination of mental health services . . . and reduced resources . . . and attempts to "dump" indigent patients across systems. . . . The mental health patient often has no clear pathway of care from crisis intervention, to in-patient stabilization, to out-patient followup with adequate social and vocational rehabilitation services. Adequate housing is often hard to find for the indigent patient who often is referred to temporary shelters. As psychiatric in-patient beds have been eliminated, jails have increasingly become housing for the behaviorally disturbed patients and often, psychotropic medications are discontinued with incarceration with little or no coordination with providers of medical care.

The parent of a Texas man with bipolar illness characterizes the causes and consequences of his son's involvement with the criminal justice system:

> I have a 28 yr. old son who has Bipolar. For 10 years I have tried to get him help. There was either a long waiting list (years), he wasn't severe enough, he was too severe, he was too poor or wasn't poor enough to qualify for programs. . . . Sadly enough, it was not until he was put in jail (on made up charges, because at the time law officers did not want the paper work or hassle of getting a mental health warrant, it was easier to take them to jail.) that he got into the Mental Health Mental Retardation services. . . . I have talked to numerous law officers confidentially over the past years and they all admit that it was easier to arrest the mentally ill on charges such as resisting an arrest, attempting to disarm a peace officer, public disturbance, etc, etc, instead of having to spend up to approx. 8 hours getting a mental health warrant/ sit at a hospital psychiatric unit. . . . Now this adds to the . . . problems [of the person with mental illness], NOW he has a criminal record for something he didn't even do!!

The theme of jailing leading to loss of psychotropic medications, often followed by a downward spiral of dysfunction is one that appears time after time in the public comments. A Pennsylvania mental health consumer describes his experience as follows:

> I have been in treatment for a comorbid panic disorder, depression, and resulting use of alcohol. Due to my mental illness, I came into contact with the criminal justice system. Much to my dismay, they have no knowledge of how to recognize a person who is mentally ill. Incarceration, and lack of access to my medications were the result. . . . Those needing the help, and understanding for their disorders, are put in jail instead. Then railroaded through the court system as criminals. Released onto the streets, with little or no help, to repeat the circle, ending back in jail, or worse.

Similarly, a South Dakota mother of a daughter with mental illness complains:

> At times these individuals wind up in jail for behaviors due to their illness, i.e. abuse or neglect of their medication. . . .I am not proposing that there should not be any punishment for the crimes they may have committed but have a real problem with how they are treated here in the jail. My specific complaint is that they are denied their medication even when it is provided free to the county . . . She gets a pill whenever they feel like giving it to her. This is extremely dangerous because there are serious reactions because of it. . . . My daughter is not the only mentally ill person being treated this way. WHAT CAN I DO? PLEASE HELP ME!

Those attempting to provide mental health services in the jail setting also express frustration with the quality of services and the inadequacy of resources:

> I am a Psychiatric Social Worker providing mental health services to inmates . . . incarcerated in our county jail. This is an area which is poorly funded and poorly staffed. This in turn limits the types of mental health services which we can provide to the inmates. . . . The SMI (seriously mentally ill) population is very underserved and lack coordinated care with the community mental resources. The population with addiction issues and the Dual Diagnosed population are also very underserved. . . . These areas need to be reviewed and properly funded for adequate staffing and adequate programs/resources/services.

A provider from Texas offers similar observations about the absence of services in the criminal justice system, and also points to the adverse consequences on return to the community setting:

> In my fifteen years in working in mental health services both in and out of the criminal justice setting, the most glaring problem was the shifting of the burden of mental health services from community based MHMR to the criminal justice settings. Jails, prisons and probation offices were the recipients of more and more people suffering from more and more severe mental illnesses and had no mechanism for referral. . . . Once someone enters the criminal justice arena, not only are their opportunities for treatment limited but once marked as a criminal, [they] can actually no longer receive some services.

Comments from two other stakeholders point out the social and financial costs associated with the jailing of people with serious mental illness:

> The costs of not treating our most vulnerable citizens is rising. The cost is reflected in the growing ranks of homeless, the Los Angeles County Jail is now the largest Mental Health Facility in the world. The cost of incarcerating a person with mental illness is far greater than the cost of treatment.

> Would we put individual's with some other physical disease in jail for treatment? We do so in our county with our children/juveniles, it is one of our Nation's biggest tragedies. This is of course how we handle the majority of the Mentally Ill adults as well. Our jails cost us money to run; it is far . . . cheaper to our society if we do not use these institutions as Mental Health wards, not to say the humane aspects of this . . .

Thoughtful comments from a range of stakeholders also point to solutions to the problem, in the form of education, diversion programs, better treatment in jail and prison settings, and better community services to lessen the likelihood of criminal justice involvement. The first comment

is from a parent in California. It is followed by a range of stakeholder observations and suggestions from other states:

> Jails and prisons are a most expensive and usually unproductive path for the mentally ill. The mentally ill who commit crimes should definitely have consequences, including serving time, and they should have medical help for their brain disorders. I don't think most judges, DA's, or lawyers understand much about mental illnesses as I heard many inappropriate, prejudiced, and uneducated comments from them during our son's trial. Judges are certainly not doing anything about providing help for the 17% of the prison/jail population that has mental illnesses. We definitely need to help the judicial system help the mentally ill. It's not their fault they don't understand; they simply need help in understanding. There are some good programs out there doing just that, and the federal government should be doing all it can to get these programs established through the US.

A nurse and mother of a son with bipolar illness also recommends educational programs:

> This topic is [of] particular interest to me as a parent of a 28 year old son who is Bipolar and has been receiving meds and treatment for the last eight years. He had completed Law School and was studying for the bar when he became very manic. . . . I teach about mental illness to Nursing Students and have worked in this area for years . . . What is needed in the criminal Justice area are classes for police officers and DA's so that they can have a better understanding about the illness and the system can work to help these individuals who are suffering with mental illness rather than punish them for delusional thinking that is not harming others.

A member of NAMI from Illinois observes:

> I was also an approved police trainer on mental health issues. But how can we expect our officer to transport a sick person for 2 hours one way to the closest Psychiatric unit and than have to come back to go to court and testify to have the person involuntarily committed. Time restraints make it easier to bring the person with mental illness to jail. . . . In jail all should have access to medication and medical services. It is inhumane to have a sick person in confinement for months, some with no bedding or clothing especially as it is the illness that brings them to jail. Confinement causes more severe illness that takes a long time to heal, if at all.

Three other stakeholders provide interesting suggestions of their own:

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I observe that we need Mental Health professionals and Local Police and Sheriff along with Judges and Lawyers to be more informed of each others responsibilities. They need to network more and keep each department aware of the needs of the Mental Health Client and the different treatment options which may be available in a particular County or City.

There is a need for discharge planning from the hospitals and the jails. People are treated and released into the community, with no one helping them find where they are supposed to go to continue their treatment, causing them to become ill all over again.

What is needed to save monies in Mental Health Reform is mandatory "Crisis Units" in all Counties of all states and a P.A.C.T. Team type approach on after care to help keep the mentally ill well and in society. The other side of this story is the 30% or more of the people in jail who should be in some sort of Mental rehabilitation program. . . . One less Jail per county built and one Crisis Unit built with a drop-in clinic in its place would be an answer that would give these Mentally Ill Americans a real chance for help and happiness.

Successful Community Participation

Despite all the barriers to recovery and community participation, a number of stakeholders tell the Commission about some successes. A parent recounts her daughter's successful recovery, which she attributes to effective treatment, particularly finding the psychotropic right medication, and supported employment:

> First, a success story. My daughter, who is 22 and suffers from severe bipolar disorder, was repeatedly hospitalized during adolescence. Gradually, the best medications for her were identified, and through quality doctors and therapists she learned to recognize and manage her systems. Now she is attending school and working full-time ... It was very difficult for her to move into 'participating fully in her community' until we FINALLY found the right medications to manage her most severe systems, so I am convinced this is the essential first step for many individuals with severe illnesses. Second, I cannot emphasize enough how important the ability to work in a real job has been to her self-esteem and therefore to her continued stability. In our state, the absence of adequate basic services, especially timely and comprehensive services for individuals suffering a relapse/crisis, means that many individuals are unable to stabilize sufficiently to make the next steps toward participating fully in the community.

This consumer expresses hopefulness that people with serious mental illness can recover, but cites many system-level barriers that stand in the way:

> I believe the "system" failed me the most as I attempted to achieve my bachelors degree. There were not enough support services available, thus it took me eighteen years to finally achieve that goal. Paying for medications, too, is a very difficult task. I hope the Commission will truly address the issues of discrimination, lack of adequate funding for community services, lack of insurance equity, and the issues of supported housing, education and employment. People with SMI can and do recover given the opportunity. Most people don't know that as a truth.

The mother of a young adult with bipolar disorder describes her daughter's fragmented mental health treatment and lapses when no mental health clinician was available to see her daughter for months at a time, and writes of her daughter's recovery:

> In spite of the problems ... all of them due to lack of service by the mental health department in this county, my daughter has regained her health to the extent that she is enrolled in the Community College and has resumed the college career that was interrupted by bipolar illness ... I have only to look at my daughter to see what a valuable contribution she will one day make to society as an art teacher for the primary grades, and think of what a loss this will be if she cannot maintain her mental health because she can't see her doctor when she is ill.

Topic 4: Programs or Practices that Work Well or Improve Your Experience of Care

Unfortunately, a number of stakeholders' comments on this topic are similar to that of this family member's:

> I cannot comment on good programs and/or model programs because I am unaware of them...

When stakeholders do cite particular programs, they most often mention the following types of programs as effective interventions that improve consumers' experience of care:

- Ongoing Medication management
- Supported employment
- Housing support
- Programs for Assertive Community Treatment (PACT)

- Integrated treatment for co-occurring substance abuse and mental illness disorders
- Consumer-run and peer-support services

Stakeholders' desires for these types of services, and the barriers that inhibit accessing them have already been addressed previously in this report:

> The P/ACT Model, as tested so far in this state, is also extremely cost-effective, as well as being a preferred practice by those who are being treated. Much less frightening than being psychotic among strangers, in a strange, locked environment, cut off from everything and everyone warmly familiar.

Rural providers, like this one, note that PACT/ACT programs may not be feasible in rural areas, but the program's key components can be adapted for rural areas:

> I do believe PACT teams are a very valuable service, but not cost-effective for many rural areas. PACT principles can be incorporated into a case management program that works with a wide range of consumers instead of limiting themselves to the most seriously mentally ill, treatment-resistant clients.

A provider describes a program to treat co-occurring mental illness and substance abuse disorders:

> In 1997, Community Mental Health joined up with the Tamalpais Day Services Center to form the "Allies" Program. These two agencies realized the need for services for dual diagnosis clients, and the importance of treating mental illness and substance abuse concurrently. The purpose of the group is to help clients learn to manage their mental illness, and hopefully learn alternatives to substance abuse...It is a safe place for people to share if they have had a drink or used drugs recently. Unlike some groups with 'no tolerance' policies, they will not be kicked out if they have started using again:

PUBLIC COMMENT CODING METHODOLOGY

The public was invited to submit comments to the President's New Freedom Commission on Mental Health via the Commission's Public Comment web site at http://www.mentalhealthcommission.gov.

The public comments submitted to the Commission Web Site were imported into an ACCESS database for coding. The Commission also received a small number of comments through the U.S. mail and email. These comments were typed into the ACCESS database for coding.

Trained staff reviewed each comment and coded its content according to a pre-determined coding scheme. The coding scheme consists of 25 categories. Fifteen of the categories represent the Commission's Subcommittee areas, while the remaining ten categories represent broad themes, cutting across Subcommittee areas, that appeared frequently in the public comments. The coding categories and their descriptions are shown in the Appendix. Westat staff first compared coding results among all coders to ensure that coding was conducted reliably and consistently across coders. The coded comments, sorted into the 25 categories, serve as the basis for this Report.

APPENDIX

Coding Categories for NFC Public Comments

Group	Category	Definition
Age	Children	Relating to MH problems or treatment for children 21 years of age or younger
	Older Adults	Relating to MH problems or treatment for persons age 60 years or older
Special Populations	Consumer Issues	Related to recovery; empowerment; consumer self-determination; consumer demands, rights, or needs; or survivor issues of persons with MI
	Criminal Justice	Relating to involvement of a person with MI with the criminal justice system, e.g., police, courts, jails, prisons, or any specific legal issues
	Families	Any discussion of family, impact on family members or a member's mental illness
	Homeless	Relating to homelessness or housing issues for persons with MI
	Rural	Relating to MH problems or treatment for persons living in rural areas
Services	Co-Occurring Disorders	Related to having both a MI and substance use disorder or co-occurring treatment
	Employment & Income Support	Related to getting, keeping, or losing a job; vocational rehab, supported employment, or jobs programs; or income supports, e.g., SSI, SSDI, or others
	Evidence Based Practices	Related to evidence-based practices for MI, model programs, or best or promising practices
	Housing	Related to access to affordable housing, lack of housing, or loss of housing
	Medicaid and Medicare	Mention of terms "Medicaid," "Medicare," "SSI," or "SSDI"
	MH Interface with General Medicine	Involving having a MI or receiving MH treatment and general medical problems or general medical treatment
	Medication Issues	Relating to medications for MI or other medications that affect MH, and interactions.
	Suicide Prevention	Relating to suicide, attempted suicide, suicidal ideation, or suicide prevention
Access	Coordination of Services	Relating to coordination of different services such as CM, SA, & MH, or within MH continuum.
	Rights and Engagement	Relating to legal rights of persons with MI and their engagement in MH services
	Cultural Competence	Relating to cultural aspects of MI and treatment, e.g., cultural, race, ethnicity, gender, age, sexual orientation, and other aspects of culture
	Financing/Reimbursement	Relating to the cost of care, insurance coverage, co-payments, limitations on what is available due to state, federal or insurers financing regulations, and lack of financing/reimbursement
	Hospital	Specifically relating to care in a hospital setting
	Policy/Regulations	State or federal level rule, policy, procedure, regulation or pending legislation relating to MH coverage
	Managed Care	Anything relating to managed care
	Parity	Relating to equitable coverage of mental health parity and physical health disorders.
	Restriction or Lack of Services	Blocked access to services due to restrictions such as entry criteria or insurance coverage, absence of services in an area, being provided the incorrect services for a particular issue, and not being directed toward appropriate care by professionals (MH or non-MH) due to lack of training.
	Stigma	Relating to stigma, discrimination relating to MH problems or receiving MH treatment
	Transportation	Lack of transportation to services, public or private
	Challenges in Community Life	Everyday challenges faced by people with MH trying to live in communities, includes overt and covert discrimination, teasing, access to services, employment, social support, etc.

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